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Involvement in meetings and events: Tips for good practice

Headline: When face-to-face meetings and events resume, there is likely to be a renewed commitment to involving people with dementia and carers. Clare Mason and colleagues reflect on what they have learnt from their own experience and provide some tips for good practice.

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There is a growing public awareness of the challenges faced by people living with dementia and their carers. This has been partly driven by dementia policy and strategies focusing on raising public awareness and understanding of dementia (Alzheimer Europe, 2018; Department of Health, 2009). Alongside this there are an increasing number of people with dementia and carers who are publicly speaking about and writing accounts of their experiences e.g. (Oliver, 2019; Mitchell, 2019). By sharing their stories this can bring an enlightenment to those who hear it, to counter the often negative portrayal of dementia (Hillman *et al*, 2018). It also places an emphasis on the 'voice' of those living with or caring for someone with dementia, that their viewpoints need to be heard and listened to. Increasingly, people with dementia and carers are being invited to share their experiences by speaking at meetings or events. This is often in conjunction with their involvement in research studies.

There is an increasing recognition of the role of 'patient and public involvement' (PPI) in both research and policy making. In particular, there has been a shift in the design and conduct of health research to focus more on the patient experience (Pickett and Murray, 2018). Rather than people just being 'participants' they can have an active role in shaping the research. There are many ways that PPI members can be involved in the research process from seeking their opinion on the research topic to being involved in the research design. However, for this to be an effective partnership there needs to be genuine collaboration, rather 'tokenistic' involvement or box ticking (Gove *et al*, 2018; Charlesworth, 2018).

Within the dementia field, there are a growing number of examples of the benefits of involving people with dementia and carers within the research process as PPI members or 'experts by experience'. Parveen *et al* (2018) involved diverse range of experts by experience in the Caregiving HOPE study, who had different roles based on their skills, experience and interests. Formed in the 2014 the ALWAYs group described in Litherland *et al* (2018) are people with dementia and carers who act as advisors to the IDEAL programme (Clare *et al*, 2014). Reporting findings from a focus group with the ALWAYs group, Litherland *et al* (2018) identified a range of gains from their involvement in the study from building confidence, giving them a role and feeling their contributions were valued by the research team.

There has been good practice guidance developed in PPI, giving a framework for meaningful PPI involvement and ensuring people are appropriately supported and compensated for their involvement. For example, ensuring payment for involvement in meetings, travel expenses, or daily allowances (INVOLVE, 2012). There are also checklists for improving the reporting of PPI in research publications (Staniszewska *et al*, 2017). However, there seems to be a lack of formal guidelines on how to involve people in a key part of the research process, dissemination. There is some guidance from the DEEP network (https://www.dementiavoices.org.uk/) on involving people with dementia at meetings and events. It is clear that involving people with dementia and/or carers in presentations in meetings or at events requires careful consideration and support. For example, Parveen *et al* (2018) describes how experts by experience members were keen to present at events but lacked the confidence to do so. With appropriate support they were able to do so, and this improved their well-being. Similarly, with support members of the ALWAYs group have co-presented at events (Litherland *et al*, 2018). Within this article we reflect on our own experiences at co-presenting at meetings and events and share recommendations for best practice in this area.

Case Study: Clare talks about involving people in meetings

Over recent years, the way we involve people living with dementia in our work has changed considerably. I have learnt from experience that preparation is important to ensure people feel welcomed, supported and confident enough to participate. This can involve providing clear and concise instructions about the location of a meeting. For example, for one meeting I provided detailed instructions of how to find the venue, including photographs of landmarks, car parks and the venue entrance. I received positive feedback from attendees who said they otherwise would not have found it. Within the building I put up signage to help people navigate the building; for example, inside and outside toilets. I also put signage on the food and catering equipment. This all supported people to feel they had an element of independence and control within the meeting and alleviated some of the anxieties that dementia presents a person who is outside their own familiar environment.

Patient and Public Involvement consists of a number of layers; the initial contact layer involves inviting people to participate, answer questions, allay fears and putting minds at rest. The next layer is sending out information and follow-up reminders which vary from

person to person based on their individual needs. You need to ensure written materials, and presentations are in an accessible format and language, and sent in advance of meetings. Feedback from Experts by Experience about the language, length and density of some documents has highlighted that getting this wrong can create negative impression and potentially result in people failing to attend or engage for fear of looking foolish. Although the preparation and support needed to involve people with dementia and their families in, meetings and conferences can be time consuming, the effort it takes can be 'make or break' of a successful event and the key to ensuring people feel inclined to return in the future.

Case study: Sahdia talks about co-presenting with carers

A key aspect of the Caregiving HOPE project was the close collaboration between researchers and family carers (relatives). Family carers were involved in all aspects of the project including: deciding on the research questions, determining how data was to be collecting, analysing the data and disseminating the findings. Over the three years, I presented our findings at several national and international conferences. Due to the nature of the project, it was important for me to present the work with carers. This was not always possible due to conference organisers often only allowing academics to attend and present at their conference. Where allowances were made for carers to attend, the issue of registration fees, travel and accommodation costs often remained. There were however several benefits to involving carers as co presenters at conferences. Often, conference delegates reported that the carer's presentation enabled the findings of the study to be shared in a more engaging manner. Delegates also found the carer's personal accounts to be interesting and impactful. For me (the researcher), the conference was made more enjoyable by the carer's presence as we were able to provide each other with moral support. Both parties supported each other with networking with new groups and made new contacts. Perhaps most importantly, the carers and I were able to develop a personal relationship and I was able to gain a deeper understanding of the caregiving experience from various perspectives. The carers who presented with me at conferences thought they gained a greater understanding of the academic world and its processes. More importantly, they felt a sense of achievement and a growth in self-confidence.

During the project, it was not just the research team inviting carers to co-present at conferences, but a number of carers invited me to speak at carer specific events. The

following allowed us to feel prepared and confident in attending each other's events and presenting:

1) Knowing who the audience would be at the event to ensure the presentation was 'pitched' appropriately.
2) Discussing in advance what we would present and what our roles would be.
3) Ensuring your presenting partner knew the address of the venue, and best methods of travelling there.
4) Supporting each other to arrive safely and on time. As I relied on public transport, often the carers would pick me up from the train station and drive me to the venue. I in turn would often book everyone's train tickets and accommodation when attending academic conferences.
5) Debrief after the event. Discuss what aspects worked well, what we enjoyed and what we could do differently next time.

Case Study: Catherine talks about her experience chairing a symposium

I organised and chaired a symposium where there were four presenters who all worked together on the IDEAL programme. Three of the presenters were academics from Universities and the other presenter was Keith (a person with dementia). To prepare I first contacted Keith and asked if he wished to present. I gave Keith a brief overview of what I would like him to talk about and how long he would have for his talk. Keith wrote a script of what he was going to say in his talk which he sent me beforehand to read so I knew what he would be talking about. Keith also prepared some slides to go alongside his presentation. With assistance from Rachael we sorted out his overnight accommodation and transportation to and from the venue. As chair my responsibility was to order the four presentations and I had put them into a logical order based on the content, which resulted in Keith being down as last to speak. However, this was before we knew the time of day we would be presenting at, which turned out to be in the afternoon. When I spoke to Keith on the day of the event he shared his concerns that it would be harder for him to concentrate later in the day so I re-ordered the presentations so he had an earlier presentation slot. Keith's talk went well as he eloquently described his experience of receiving a diagnosis and life post-diagnosis. Normally after presentations the audience can ask questions, but Keith

made it clear to me that he was tired after his talk so I just Informed the audience that we wouldn't be taking any questions at that time.

On reflection what I learnt for organising the event was the importance of preparation. If you are asking someone to speak at an event you need to provide an overview of what you would like them to talk about and for how long for so that they can prepare appropriately. By Keith writing a script for his talk this helped him to keep on track and on time. Keith is experienced at speaking in front of audiences but someone else may have needed more support, in these situations it may be better to co-present alongside them. Last, it's important to be responsive to the situation and supportive, I was able to change the time of Keith's presentation slot and stepped in when he requested no questions after his talk.

Case study: Clare and Michael talk about their experience presenting at a conference

Clare writes about how they prepared: Michael and I co-presented at a conference in 2019 about a study that Michael had participated in. To prepare, Michael and I discussed his experience of being a study participant. I typed his words verbatim and then we extracted the key points Michael felt he wanted to get across. I put the material onto slides with some pictures. I then emailed the presentation to Michael and he made final changes. We were able to discuss the presentation during the conference and had a short rehearsal, agreeing who would present when. At the presentation Michael had a printed copy of the slides and I had them on my iPad. Over time we've built up a good rapport with one another and felt this came across during our presentation. I was able to prompt Michael if he got stuck and (hopefully) he knew I would support him if he needed it.

Michael writes: When I was asked if I would do a presentation I jumped at the chance but then got nervous when I was asked if I could make my own way to the conference venue, which would involve multiple journeys. I found that this was going to take me out of my comfort zone, and I knew from past experience that I would start to get confused. I explained this to the study team and was reassured that they would not want to give me a bad experience so other arrangements were made. The arrangement was I would travel with Clare and stay in a hotel for the two nights of the conference.

At the conference I helped at a stand for the MSc in Advanced Dementia Studies at Bradford University, accompanied by one of the current MSc students. I was able to attend some of

the other talks at the conference with this MSc student which I enjoyed. Clare and I had a trial run of our presentation, which was helpful. On the day of the presentation the main challenge was you had to get up onto a platform to do the talk which was hard for me to see as it was the same colour as the floor. I was thinking please don't fall getting onto the platform or getting off it. Another challenge was that I couldn't see the screen, so I didn't know where we were in the presentation. To deal with this I was asked “do you want to tell us about?” and then that would remind me what was next. When presenting I had forgotten some of the things we talked about in the trial run. Nerves were part of this, as you are talking to an audience of people you've never seen before. However, Clare was very supportive

Overall, what helped me with the presentation was feeling supported. If I wasn't sure about something I could always ask, and I was always asked if there was anything which would help me. This helped me feel that I was not under pressure. Having a trial run of the presentation was helpful. If anyone is thinking of doing a presentation then I would tell them to do it, they are not going to be judged. People need to know about the impact dementia has on the person living with it and their families, and the only way to do it is to tell people. If I can do it then anyone can.

Conclusion

As our case studies indicate, your primary goal as someone organising a presentation should be that people with dementia and carers leave the meeting or event feeling that it was a good experience and their contributions were valued. Where necessary think about how you might inspire prospective speakers to feel confident, such as involving more than one person with dementai so that they can offer each other peer support. Always talk to people about how you best support them. By giving yourself time to allay any worries and questions, you can do much to make your contributions to conferences and events successful and rewarding.

Overall recommendations

Your primary goal should be that people with dementia and carers leave the meeting or event *feeling* that it was a good experience and that their contributions were valued. Involving more than one person with dementia helps to create confidence and peer

support. The best way to prepare is to talk to people about how best you might support them; this gives you time to allay any worries and answer questions.

Be clear what you want from people in the context of the overall plan for the day

Do you want a formal presentation? Is it a round table discussion? Perhaps an interview or film would work best? Let people know if there are particular restrictions such as the length of time allocated to them on the agenda. The best approach is to discuss preferred contribution styles and methods with the person

Ensure you have given yourself enough planning time

The longer lead in time the better. Last minute requests for input are stressful. Start your support a long time before the actual day.

Make sure there is support for the person to attend

Assistance with travel helps (e.g. booking transport), an accessible map that can help people find the venue, meeting and greeting people at transport hubs, a named contact person throughout– these all help to provide reassurance.

Keep in touch

Don't just expect a person to turn up at your event, contribute and go away again.

Have a contingency plan

As part of your planning, pre-empt as many eventualities as you can especially: what will you do if someone cannot contribute on the day? Could another person with dementia step in, perhaps drawing on the contributions the original person would have made? Perhaps there is a film you can show instead?

Follow up after the event

Thank people for their time (a thankyou card can mean a lot to people) and let them know how their contribution was received. Ensure any expenses are paid quickly (and any

payments for their time). Find out how it felt for the person with dementia and/or carer. This is your most valuable feedback for preparing for future meetings and events.

More information

DEEP have written guides of best practice in involving people with dementia, these can be found here: https://www.dementiavoices.org.uk/deep-guides/

To find out more about the work of the Centre of Applied Dementia Studies, including our MSc in Advanced Dementia Studies, please go to: https://www.bradford.ac.uk/dementia/

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